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June 11, 2017

Honorable Eleanor L. Ross
 United States District Court
 Northern District of Georgia
 1788 Richard B. Russell Federal Building and United States Courthouse
 75 Ted Turner Drive, SW Chambers:1788
 Atlanta, GA 30303-3309

Re: Case 1:16-cv-03088-ELR USA v. State of Georgia

Honorable Eleanor L. Ross,

Please allow me to share with you and all parties involved in the above referenced case, a copy of my letter to Ms. Alexa Ross, regarding the current and ongoing segregation of children with disabilities to a Georgia Network for Educational and Therapeutic Services (GNETS) Center for instruction (Exhibit #1). Apparently, the U.S. DOJ complaint has done little to address the harm of segregation in the State of Georgia and there is a continued disregard for laws regarding the education of vulnerable children. It's the "federal government can't tell us what to do" mentality ingrained in many in Georgia. They forget that the framers of The U.S. Constitution had a reason for establishing three branches of government.

Please forgive me if this letter is out of order. However, I felt that as a responsible citizen, a former volunteer Guardian Ad Litem and more importantly, a Christian, I had no choice but to write to you and share the harm I have personally witnessed over my 20 years of volunteer advocacy work for children in Georgia's education system including the GNETS Centers. I pray it does not fall on deaf ears for political expediency, as the lives and future of our most valuable resource, our God given children, depend on it.

I agree the federal government shouldn't dictate or interfere with local and state decisions, but when Georgia leaders, our state and local government agencies and representatives ignore years of complaints about violations of the Americans with Disabilities Act, the Individuals with Disabilities Education Act and other laws, as well as the physical and emotional harm of vulnerable children they are elected and appointed to serve, there is no choice but to use the three branches of government and the judicial system in desperate hope of seeking resolution. Unfortunately, many families do not have the financial resources to do so.

The families who do have the financial means end up signing nondisclosure agreements like the one in the Stephan Ferrari case, who suffered physical and emotional harm in a GNETS Center in Atlanta¹. Parents, advocates or others who file complaints with local, state or federal agencies end up having their children and families retaliated against, so parents, teachers and professionals are silenced and countless children continue to suffer harm without recourse.

For decades, when resolutions to complaints are reached between the attorneys of the U.S. Dept. of Justice, the U.S. Dept. of Education, the State of Georgia, the Georgia Department of Education (GaDOE), the Local Education Agencies and district schools, they agree to improve the ability of states, districts and schools to serve students by sustaining and funding more of the same flawed "therapeutic and educational supports and services" framework called Positive Behavioral Supports (PBS) a.k.a. Positive Behavioral Interventions & Supports (PBIS)².

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More funding is then requested for technical assistance in PBIS training, Functional Behavioral Assessments (FBA) and Behavior Intervention Plans (BIP) through grants and other financial sources from the United States government agencies and partnerships. The funding is funneled from the U.S. Department of Education agencies including but not limited to the Office of Special Education Programs (OSEP) Technical Assistance Center for PBIS (PBIS TA Center)², the U.S. Department of Health and Human Services and their respective agencies, including Centers for Medicare and Medicaid Services, the Federally Funded Research and Developmental Centers (FFRDC) and other public-private partnerships like Autism Speaks, to the State of Georgia and its agencies. These include but are not limited to the GaDOE, Local Education Agencies (LEAs) and individual schools despite repeated complaints about the physical, psychological and emotional harm to children in GNETS and general education school setting using the same failed and flawed therapeutic and educational supports and services for over 40 years.

The U.S. Dept. of Justice rightfully claims segregation harms children but fails to report the emotional and physical harm of the suggested resolution: the same supports and services that has harmed children physically and emotionally. Basically, the continued use of children as guinea pigs in experimental analysis while attending the general education setting. More funds will be sent by the U.S. Department of Education to OSEP's Technical Assistance Center for PBIS (PBIS TA Center)² and the other federal agencies named above to the State of Georgia and their respective agencies and partners, which includes OSEP's PBIS Technical Assistance partner in Georgia³ – the Georgia Department of Education Office of Standards, Instruction and Assessment, the LEAs, the Regional Education Service Agencies (RESA) and other SWIS facilitators and PBIS Coordinators in schools and community based centers³

I have no doubt that many involved in promoting these interventions are well-intentioned, but for some who financially benefit from recommending more funding for the same failed and flawed behavioral interventions and services - our children have become political pawns and are used to advance political and research agendas. Our children become guinea pigs when parents have no choice and are mandated to have their children subjected to “therapeutic and educational supports and services” regardless of potential for harm. In some cases, when the child is harmed the school uses compulsory attendance laws in court to force the parent to return the child to school. I have witnessed this several times.

Adults have shared the harm they experienced when these same therapeutic educational supports and services were used on them in our education system. Some researchers have voiced concerns about the harm coming to children to government officials and agencies, but the funding continues for decades, without regard for harm to children.

I was trained in PBIS by a behaviorist of OSEP's Technical Assistance Center for PBIS. I, and others, including behaviorists, identified several flaws in the FBA data collection process and documentation that results in countless children being emotionally harmed in Georgia and throughout the United States. The flaws were identified and known by behavioral experts since the Clinton administration, ignored by subsequent administrations and continues today.

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The PBS process starts in the general education setting as School-Wide Interventions and Supports (SWIS). Problem behaviors are identified in a child, and a meeting, usually an Individual Education Plan (IEP) team meeting, is called to discuss and request the need for a Functional Behavior Assessment (FBA). The team agrees on the need for teachers, parents and other professionals to collect data (date/time of antecedents, behaviors, consequences) on the identified problem behaviors for no less than 10 days. The data is then analyzed and, more often than they care to admit, an erroneous hypothesis is formed as to the function of the behavior. A Behavior Intervention Plan (BIP) is then developed in a futile attempt to modify a child's behavior. When the BIP repeatedly fails to modify the behavior of the child in the regular school setting, the process starts all over again. After many, sometimes years, of failed FBAs and BIPs the child's behavior gets progressively worse and many times results in frustration, anxiety, depression and other emotional and behavioral manifestations, and then the child is referred to a more restrictive environment like GNETS or other Community Based Centers for "intensive behavior intervention services".

Unfortunately, many parents, teachers, and certified PBS specialists are not told about the flaws in the FBA data collection process, nor are they informed that when the FBA and BIP repeatedly fails to address the problem behaviors or "in a case where the hypothesis is difficult to establish or when problem behavior is particularly resistant to intervention, a functional "analysis" may be recommended".⁴ A Functional Analysis (FA) involves a "systematic manipulation of factors that are hypothesized as triggering or occasioning problem behavior".⁴ These manipulations are designed to purposely "trigger problem behavior"⁴ repeatedly "to test the hypothesis".⁴ This can lead to trauma.

Imagine an unsuspecting parent who takes their child, whose target behavior is screaming or head banging, to a GNETS or Community based center without knowing the risk of irreparable harm. As described by a former employee of the Marcus Autism Center: The child is put in an isolated room and a trained behaviorist puts on protective gear. The behaviorist purposely triggers the problem behavior (screaming, banging of head, etc.) of the child repeatedly to collect data. Some children end up with PTSD or become withdrawn and depressed, others become aggressive or suicidal. Some children withdraw from the parent who took them to be assessed and from society in general.

In Jonathan King's case, he hanged himself in a North Georgia GNETS Center. I was involved in a case where a child became suicidal in another GNETS Center. In another case I was involved in the child was sent by the local school to a GNETS Center for assessment and the child came home banging his head. In 2013, I was involved in another case where a child was physically and emotionally harmed in a GNETS Center and became depressed. These are just a few of the cases in GNETS but there are more and others reported to the U.S. Department of Justice Civil Rights Division. There are also more stories about abuse and harm in the general education settings when PBS is used in the general education setting.

The GaDOE established a rule to report harm, but the data is often not reported in the published research because "harms data are typically not reported in nonmedical studies, although potential for harms of behavioral and other interventions should not be discounted"⁵.

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Legislators, educators and parents should use caution when using the Comparative Effectiveness Reviews of Effective Healthcare Programs published by the Agency for Healthcare and Research Quality (AHRQ) for making decisions on interventions or funding. There is a lack of integrity in data reporting and I have found conflicts of interest that were not disclosed by those who benefit from recommending more funding for behavioral intervention research. Unfortunately, the same is true for some peer reviewers.

Therapeutic and educational supports and services are touted as “evidence based” interventions even though many in the research and education community know “little evidence of practical effectiveness or feasibility exists”⁶.

In 2014, the Baylor College of Medicine in Houston, Texas published a summary of two AHRQ Comparative Effectiveness Reviews (No. 26 and No. 137), which included the Behavioral Interventions Update. It concluded the following gaps in knowledge remain: “There are no or few studies that describe the following: Whether there are any harms associated with behavioral, educational, allied health, or CAM interventions.”⁷ “There are consistent results from good-quality studies. Further research is very unlikely to change the conclusions.”⁷

The May 2017 Comparative Effectiveness Review #189 prepared for the AHRQ is hard to compare since medications were used in combination with behavioral interventions and harm data reporting was inconsistent. Still, the review states “Few studies provided data on long-term outcomes after cessation of treatment. Future studies should extend the follow-up period and assess the degree to which outcomes are durable in “real world” situations⁸. For years the results have been the same in effectiveness reviews because these interventions are based on behavior modification through an extrinsic motivation model. Research has shown time and again the failure of this methodology and the harm it can cause to a human’s intrinsic motivation.

Basically, the therapeutic educational supports and services, which are based in Applied Behavioral Analysis (ABA), have not been proven to be effective after the treatment period and there is no evidence as to long-term positive outcomes outside of a controlled setting. The above is what we have after over 40 years of research and complaints of harm to Federal, State, Local Education Agencies and the various government agencies that receive millions to protect and advocate for the civil rights of our vulnerable children.

Parents are not well informed of the possible harm nor are they given choices as to what therapeutic educational supports and services are used, even though the education system and researchers know of the potential for harm. Government agencies say they don’t dictate any one therapy over another, but that is simply not true. The decision to fund specific therapeutic educational supports and services is made at the federal level and it’s funneled to the states, districts and schools.

There was public outrage over the emotional abuse of prisoners of war and an outcry for justice because the United States doesn’t allow psychological experiments on prisoners of war. Yet, we use intensive experimental analysis on children and call it “therapeutic educational supports and services”, while ignoring decades of harm.

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If parents, advocates or professionals complain or call an advocate, their children and families are retaliated against. Behaviorists keep quiet for fear of "never working again". Teachers and administrators fear losing their jobs if they disagree or speak up. Agencies fear losing funding if they disagree. All remain silent because of fear.

Who is left to speak for the harm and travesty of justice suffered by children in our education system? How long will we continue to allow children to be used as guinea pigs and harmed because everyone fears speaking the truth? I can only pray that the plight of our children and their families will soon end and my pleas for effective and meaningful resolution does not fall on deaf ears.

Thank you for your time and consideration.

Respectfully,

Carmen Allen
Advocate
678-617-3655

Cc:

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Sources:

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Attachment # 1

From: C Allen [mailto:bc_its_right@yahoo.com]
Sent: Thursday, June 08, 2017 2:54 PM
To: Alexa Ross
Subject: GNETS DOJ Complaint and Students with Disabilities

Ms. Ross,

My name is Carmen Allen and I'm a volunteer advocate for Students with Disabilities (SWD) in Georgia.

Recently, it was brought to my attention that some Local Education Agencies in Georgia were having ALL SWD attend ESY in a GNET facility instead of allowing them to attend Summer school with their peers or receive ESY in the school they have been attending.

My understanding is that there were no choices or other individualized options allowed to be considered. The decision was made unilaterally for ALL SWD.

Is this what the proposed new rule 160-4-7-.15 means by "GNETS is a service"?

To be candid, I've not called the LEAs because I don't want to subject the students or their parents to retaliation, as has happened in the past. I have confirmed, by other means, the information is accurate for at least one LEA.

Isn't providing educational supports and services in the most integrated setting appropriate to the individual child's needs, in part, what the DOJ complaint is about? If so, then please be so kind as to talk to the GaDOE and help educate the LEAs. If not, then I'm sorry for wasting your time. I can file a separate DOJ or OCR complaint to address the continued discrimination of SWD by not allowing them to attend Summer school with their peers and segregating them to a GNET building for ESY instead of serving them in the regular school setting, where they were attending, with their peers.

For the record, I am not involved in any way with the DOJ complaint. I'm simply a volunteer advocate that parents, educators and students trust and call because of the work I've done in communities throughout the state.

I look forward to a response.

Thank you for your time and consideration.

Respectfully,

Carmen Allen

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